February 24, 2023

Paula Jones 5 Bear Ridge Dr Bloomfield, CT 06002

Public Hearing Monday, February 27, 2023

Re: Support for HB 1076 An Act Concerning Aid in Dying for Terminally III Patients

Members of the Public Health Committee:

Thank your for the opportunity to submit written testimony. I am writing in strong support of SB 1076, An Act Concerning Aid in Dying for Terminally III Patients.

As a humanist, I've been following the Medical Aid in Dying issue since 2013 and hope this is finally the year that the General Assembly will pass a bill – it's past time. Connecticut residents facing a terminal illness deserve a full range of options for care at the end of life, including medical aid to end their lives peacefully and without suffering.

Over the years, humanist groups I belong to have hosted discussions on the topic of Aid in Dying. One time a disability activist from Second Thoughts Connecticut was invited to present objections to Aid-in-Dying legislation. Attendees listened to and tried to understand her viewpoint. That view was shaped by fear: fear that the disabled and the elderly will be pressured into ending their lives because they are perceived as a "burden" on society or to their families and friends. No amount of explanation that this was not what was in the proposed legislation made any difference; fear is a powerful emotion and trumped all reason. SB 1076 is well-crafted, applies only to the terminally ill, and has multiple safeguards in place to prevent abuses. SB 1076 is modeled on the Oregon law, which has been in place for over 20 years without these alarming outcomes.

I'm 66, so like anyone my age, I've had my share of loss. Two instances, separated in time by 30 years, come to mind.

In the first instance, my closest childhood friend, Anne, went for a bike ride, fell off her bike, and was in a coma for months. She was 32 years old, living in Manchester, CT, and married with a toddler. Anne delivered her second child by C-section while in a coma, eventually regaining consciousness. When she did "wake up" she could only move her eyes and was diagnosed with Locked In Syndrome. She ultimately decided that she did not want to live this way, and communicated to her family members (through eye movements) that she wanted to refuse additional medical treatment and have her feeding tube removed.

Anne had always been physically active, cycling cross-country after graduation from UCONN, so being bedridden and completely dependent on caregivers for the rest of whatever life she had wasn't acceptable to her. After a lengthy process involving physicians, lawyers, and the court system, her feeding tube was removed and she was discharged from a long-term care facility and allowed to go home to die. Under the provisions of SB 1076 a medical prescription wouldn't have been an option for her for two reasons: she couldn't self-administer the medication, and the condition, while terminal, generally lasts much longer than 6 months. I offer my friend's story as an example of the extreme lengths she and her family went to in order to allow her to die on her own terms. She fought to die. The experience was hell for her family, and a testament of their love and advocacy for her. While the bill under consideration wouldn't have applied in her case, it is an important start along the path of alleviating such suffering.

The second instance is more recent. A friend suffering from terminal cancer would have appreciated having this option before her death. She was an incredibly strong person who really fought to live. I can never know whether she would have used medication to die at a time of her choosing instead of hanging on until the end. But I am certain that simply having this additional option would have given her a greater feeling of agency and control at the end of her life, something that was extremely important to her throughout her life. Having agency and control, being free from debilitating pain – I think most of us want these things at the end of life. I know I do for myself and my loved ones.

Please vote this bill out of Committee and support it going to the floor for a vote. Thank you for your consideration.

Cc:

Representative Bobby Gibson Senator Douglas McCrory Senator Derek Slap